



ShareGivers Program Overview

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What is ShareGivers?

- ☀ Peer visitor program for stroke survivors and their families.
- ☀ Peer visitors are stroke survivors and caregivers who have completed the ShareGivers training course.
- ☀ Peer visits are made to newly diagnosed stroke survivors and their family caregivers at hospitals, rehabilitation centers, nursing homes, and other inpatient facilities.
- ☀ Developed by the American Stroke Association

Background

- ☀ Stroke is the 3rd leading cause of death in the United States. (Lloyd et al., 2009)
- ☀ Each year, 795,000 people experience a stroke.
(Lloyd et al., 2009)
 - 610,000 are first attacks
 - 185,000 are recurrent attacks (23%)

Background

- ☀ Prevention of a second stroke through risk factor management is critical. (Sacco et al., 2006).

- Hypertension
- Atrial Fibrillation and other cardiac conditions
- Diabetes
- High Lipids (Cholesterol and Triglycerides)
- Cigarette smoking
- Heavy alcohol consumption
- Obesity
- Lack of physical activity

- ☀ Management of these risk factors often require complex and difficult: (Sacco et al., 2006).

- Lifestyle modifications (including exercise)
- Dietary guidelines
- Medication regimes

Background

- ☀ Stroke is a leading cause of severe, long-term disability. (Lloyd et al., 2009)
- ☀ Among ischemic stroke survivors ≥ 65 years of age, at 6 months after stroke: (Lloyd et al., 2009)
 - 50% had some hemiparesis
 - 30% unable to walk without assistance
 - 26% were dependent in ADL
 - 19% had aphasia
 - 35% had depressive symptoms
 - 26% were institutionalized in a nursing home
- ☀ These stroke-related impairments and consequences make it very difficult for survivors to reintegrate back into the community.

Background

- ✱ Approximately 68% to 74% of all stroke survivors require care in the home by family members. (Dewey et al., 2001; Dorsey & Vaca, 1998).
- ✱ Caregiver stress is a leading cause of costly long-term institutionalization of stroke survivors (Han & Haley, 1999).
- ✱ Lack of appropriate discharge planning along with early discharge of stroke survivors can place unrealistic demands on caregivers. (Anderson et al., 2000; Ski & O'Connell, 2007).

Background

★ Stroke Caregiver Needs and Concerns (Bakas et al, 2002).

- Finding information about stroke
- Managing the survivor's emotions and behaviors
- Providing physical care
- Providing Instrumental care
- Dealing with one's own personal responses to providing care
 - Caregiver emotions
 - New responsibilities
 - Asking family and friends for help
 - Keeping own social life going
 - Taking care of one's own health

Background

★ ASA Recommendations for the Establishment of Stroke Systems of Care. (Schwamm et al., 2005).

- ★ A stroke system should support educational programs that target high-risk populations (such as those with previous stroke) and their families.
- A stroke system should ensure that stroke patients and their families receive education about stroke risk factors and warning signs.
- ★ A stroke system should establish support systems to ensure that patients discharged from hospitals and other facilities to their homes have appropriate follow-up.
 - Includes education and training for the patient and his or her family members.

Background

★ AHA/ASA Endorsed Practice Guidelines: Management of Adult Stroke Rehabilitation Care. (Duncan et al., 2005).

- Patient and family education improves informed decision-making, social adjustment, and maintenance of rehabilitation gains.
- Recommend that providers be alert to the stress on the family/caregiver, ... and providing support, as indicated.
- Recommend that patients and families be given information, advice, and the opportunity to talk about the impact of the illness on their lives.

Purpose of the ShareGivers Program

- ✦ To educate stroke survivors and their families about stroke
- ✦ To provide hope and encouragement to stroke survivors and their families
- ✦ To make a difference in people's lives
- ✦ To promote collaboration between the American Stroke Association and community partners (e.g. hospitals) to help stroke survivors and their families live with stroke.

Purpose of the ShareGivers Program

- ✱ Does not interfere with stroke treatment by healthcare providers
- ✱ Supplement to enhance the professional care of stroke survivors and their families.
- ✱ Accessible as a kit – and also available online.
 - Call the Warmline 1-888-4-STROKE (478-7653)
 - Visit StrokeAssociation.org/ShareGivers to register.

ShareGivers Program Models

- ✴ Community-based model
 - ✴ Involves 2 or more health care facilities
 - ✴ Each facility has a site coordinator
- ✴ Self-contained model
 - ✴ Launched by a single facility

ShareGivers Core Team

- ★ Team Leader (usually healthcare professional)
 - Enrolls key stakeholders in vision, goals, and objectives
 - Facilitates acceptance of the program in the community
 - Enrolls Education Coordinator and Site Supervisor(s)
 - May serve as Team Leader and Education Coordinator
 - Chairs team meetings
- ★ Education Coordinator (access to healthcare professionals)
 - Implementing and sustaining program
 - Conducts screening, selection, and training of peer visitors
 - Logistics coordinator, counselor, mentor, motivator
- ★ Site Supervisor (usually healthcare professional or staff)
 - Coordinates visiting services at facility after training program
 - Monitoring and evaluating visits over time
 - Provides counseling support to visitors, survivors, and families

Timeline

☀ 6-10 months prior to training

- Convene initial meeting of Core Team
- Assess community readiness and feasibility
- Establish goals and objectives
- Establish training course dates and general logistics
- Assess needs, costs, gaps, & sponsorships
- Contact local ASA for advice

☀ 4-8 months prior to training

- Promotional activities to recruit peer visitor candidates
- Planning and preparation for training

Timeline

☀ 2-4 months prior to training

- Visitor recruitment, screening and selection process
- Establish policies and processes for on-site visits

☀ As training conducted

- Promote availability of ShareGivers program

☀ 1-3 months after completion of training

- Overall program evaluation

Peer Visitors

- ☀ Peer visitors can be:
 - ☀ Stroke survivor
 - ☀ Family caregiver or someone who has lived with a stroke survivor
- ☀ Healthy and able to participate in the 12-week program and able to make visits after training
- ☀ At least 18 months post-stroke
- ☀ Have a mature attitude toward their own stroke
- ☀ Committed to helping stroke families address emotional and social concerns
- ☀ Supporters of conventional stroke rehabilitation programs
- ☀ Personal integrity with a track record of respecting confidentiality

Class structure

- ★ Lessons 1-8 (Education sessions) meet weekly for 1 ½ to 2 hours
 - ★ Class size of 12-16 stroke survivors and their family members (typically 1 per survivor)
- ★ Lessons 9-12 (Peer visitor training) meet weekly for 2 to 2 ½ hours
 - ★ Class size of 12 or less peer visitor candidates (stroke survivors and family members who wish to become peer visitors).
- ★ Graduation ceremony

Lesson 1

✦ Exploring the Facts and Figures of Stroke

- ✦ Overview of ShareGivers training course
- ✦ Build knowledge base about causes, etiology, and treatment of strokes
- ✦ Includes risk factors and warning signs for stroke
 - Sudden weakness or numbness of the face, arm, or leg
 - Sudden confusion, trouble speaking, or understanding
 - Sudden trouble seeing in one or both eyes
 - Sudden trouble walking, dizziness, loss of balance
 - Sudden severe headaches with no known cause

Lesson 2

✦ Exploring the Benefits of a Rehabilitation Team

- ✦ Rehabilitation as an ongoing process
- ✦ Define own rehabilitation plan
- ✦ Communicating needs to appropriate healthcare professionals
- ✦ Dealing with aphasia

Lesson 3

✦ Exploring the How and Why of Living with a Disability

- Health challenges of living with stroke
- Self-care strategies for managing these challenges
 - Short-term memory loss, problem solving
 - Behavior and fatigue
 - Medication management
 - Nutritional management
 - Managing high blood pressure

Lesson 4

- ✦ Exploring the Emotional Aspects of Well-Being
 - How stroke affects emotions
 - Healthy ways to express feelings to others
 - Stress management strategies and positive self talk

Lesson 5

✦ Exploring the Meaning of Self-Esteem and Intimacy

- ✦ How stroke creates changes in:
 - Body image
 - Self-esteem
 - Roles and relationships
 - Sexual intimacy
- ✦ Find ways to affirm positive changes

Lesson 6

✦ Exploring Creative Ways to Encourage a Positive Lifestyle

- ✦ Ways of maintaining health while living with disabilities
 - Proper nutrition
 - Exercise to the best of one's ability
 - Monitor blood pressure
 - Intellectual learning and new ideas
 - Social activities
 - Emotional well-being
 - Spiritual well-being (meaning and purpose in life, faith)

Lesson 7

✴ Exploring Financial Wellness

- ✴ Finding resources in the community
- ✴ Ways of managing finances
 - Personal savings
 - Disability benefits, etc.
 - Legal issues, living wills, etc.
- Possibility of returning to work
- Living arrangements

Lesson 8

✦ Exploring Emotional Wellness and Living in the Present

- ✦ Characteristics of a thriving survivor
- ✦ Value of living in the present
- ✦ Community resources



Education Certificate

This Certificate of Recognition
Is hereby granted to

On this day

For successfully completing the stroke educator
course requirements for ShareGivers, a peer
visitor program.

Lesson 9

☀ Introduction to Peer Visiting

- Rationale behind peer visiting
- Peer visitor guidelines
- Active Listening Skills I
 - Encourage person to share
 - Show you are interested and understand
 - Learn caution before giving advice
 - Stay focused on person's story and feelings
 - Respect for family's values and feelings
- Role Playing

Lesson 10

☀ Visitor-Client Relationships

- Identify unique qualities of peer visitor
- How to meet and greet new stroke families
- Active Listening Skills II
 - Show you Understand (rephrase what you hear)
 - Ask open ended questions
- Role Playing

Lesson 11

☀ Handling Difficult Situations as a Visitor

- Identify challenging situations
- How to handle challenging situations
- How and when to make referrals
- How to recognize depression and suicide potential
- Active Listening and Role Playing

Lesson 12

✴ Exploring the Visitor-Supervisor Relationship

- ✴ Clarify relationships among
 - Peer visitors
 - ShareGivers Site Supervisors
 - Cosponsoring agencies
- ✴ Active Listening and Role Playing



Diploma of Graduation

This Diploma of Graduation
Is hereby granted to

On this day

For successfully completing the course
requirements for becoming an active visitor
for ShareGivers, a peer visitor program.

Resources in the Sharegivers Kit

- ☀ Program guide
- ☀ Job descriptions for
 - Team leader
 - Education coordinator
 - Site supervisor
 - Peer visitors (along with screening questionnaire)
- ☀ Timeline
- ☀ Evaluation forms
- ☀ Certification tests
- ☀ Visit reports
- ☀ ASA fact sheets
- ☀ The 12 Lesson plans

Resources in the Sharegivers Kit

☀ DVD Video Clips

• Gift of caring

- Experiences of family caregivers
- Suggestions and advice

• Recovering after stroke

- Experiences of stroke survivors
- Lifestyle changes and rehabilitation

• You're not alone

- Emphasizes positive attitudes and benefits of support groups

• What is aphasia

- Covers different types of aphasia
- Experiences of aphasic survivors and their caregivers

• Additional ASA resources

- Warmline answered by peer survivors and caregivers
- Stroke Connection Magazine
- Pamphlets and patient education materials
- Online resource center
- Access to support groups in your area

Additional Suggestions

- ✱ Use most of the materials provided in the ShareGivers program kit.
- ✱ Realize that every peer visit is different
- ✱ Have new peer visitors co-visit with experienced peer visitors
- ✱ Remember to give peer visitors feedback

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Thank you!

